



European
Commission

Agenda

JRC Rare Diseases Registries Workshop

Baveno, Italy

19-20 February 2018

**The European Commission's
science and knowledge service**

Joint Research Centre

Joint
Research
Centre

JRC Mission

As the science and knowledge service of the European Commission, the Joint Research Centre's mission is to support EU policies with independent evidence throughout the whole policy cycle.



EU Science Hub
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EU Science Hub - Joint Research Centre



Joint Research Centre



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JRC Rare Diseases Registries Workshop
19 - 20 February, 2018
Hotel Splendid, V. Sempione 12 – Baveno (VB), Italy

Day 1 – Monday, 19 February

12:00 - 13:00 – Workshop Registration

13:00 - 14:00 – Welcome lunch

14:00 – 16:00 – Session 1

14:00 – Introduction

- Welcome and presentation of the JRC – C. Nicholl
- EU RD Platform overview – S. Martin

14:45 – ERDRI.mdr: The Central Metadata Repository Theory – H. Storf

16:00 – Coffee break

16:30 – 19:00 – Session 2

16:30 – ERDRI.mdr: The Central Metadata Repository Practical Use – H. Storf

18:00 – Discussion – Q & A session

19:00 – End of day 1

19:30 – Dinner

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Day 2 – Tuesday, 20 February

09:00 – 13:00 – Session 3

09:00 – ERDRI.dor: The European Directory of Registries Theory – T. Panholzer

10:30 – Coffee break

11:00 – ERDRI.dor: The European Directory of Registries Practical Use – T. Panholzer

11:50 – Authentication with EU-login – E. Ben

12:00 – Discussion – Q & A session

13:00 – 14:00 Lunch

14:00 – End of the meeting and departures